

## **Participant Information Sheet**

### **PPI Co-design Workshops**

**Project Title: Co-designing a person-centred nutrition programme to support nutritional recovery after critical illness**

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#### **Introduction**

You are being invited to take part in a series of workshops to help develop a nutrition programme for people recovering after critical illness.

Before you decide whether to join, it is important for you to understand why these workshops are being held and what taking part would involve. Please take time to read the following information carefully and discuss it with others if you wish.

These workshops are part of patient and public involvement (PPI) and co-design work. They are not research themselves, and formal research ethics committee approval is therefore not required. However, it is still important that anyone considering taking part is given clear information about the purpose of the workshops and what involvement will mean.

Please ask if there is anything that is unclear or if you would like more information.

#### **What are these workshops about?**

Many people find eating well and rebuilding strength after a critical illness harder than they expected. In the weeks and months after leaving hospital, people may experience problems such as poor appetite, tiredness, changes in taste or smell, nausea, low mood, anxiety, and worries about food. These challenges can make it difficult to meet nutrition needs, regain strength, and feel confident about eating again.

Support for nutrition after discharge from intensive care can vary depending on where someone lives and what services are available.

Earlier stages of this wider project have involved reviewing existing evidence and speaking with people who have experienced critical illness about their recovery. What we have learned so far is that nutrition recovery is not only about physical healing. It is also influenced by confidence, emotions, family support, healthcare support, and access to the right help at the right time.

These workshops will bring together people with lived experience, carers, and healthcare professionals to help design a practical, person-centred nutrition programme. The ideas developed in the workshops will help shape a future research study to test the programme in practice.

### **Why have I been invited?**

You have been invited because your views and experience could help us design a better nutrition programme for people recovering after critical illness.

You may be invited because you are:

- Someone who has experienced critical illness and recovery after ICU
- A family member or carer of someone who was critically ill
- A healthcare professional involved in supporting recovery after ICU

We want to include a range of perspectives so that the programme is relevant, practical and acceptable to the people who may use or deliver it.

### **Why is PPI important in this project?**

These workshops are being held because the programme should be shaped by the people it is intended to support, as well as by those involved in providing care.

Your knowledge and experience can help us understand:

- what support people recovering after critical illness really need
- what feels realistic and helpful in everyday life
- what might make it easier or harder for people to use the programme
- what outcomes matter most to patients and families
- how a future programme could work in practice

### **What will taking part involve?**

If you choose to get involved, you will be invited to join a small online group for three workshops.

The workshops will include a mix of :

- people who have lived experienced ICU
- family member or carers
- healthcare professionals.

Each workshop will last about 90 minutes and will take place online using Microsoft Teams. The workshops are expected to take place over approximately 8 weeks during June and July 2026.

During the workshops, I will share short, easy-to-understand summaries of what we know already from earlier parts of the project and from existing research. I will then ask for your views on what a good nutrition programme should include, how it should be organised, how it could be delivered, and what outcomes matter most to patients and families.

There is no right or wrong answers. We are interested in your ideas, views and experiences. If you are someone with lived experience of critical illness or a carer, you do not need any medical knowledge or specialist preparation. You are welcome to contribute as much or as little as you feel comfortable with. You do not have to answer any questions and may simply listen if you prefer.

If you are invited to all three workshops but are unable to attend one because of health, caring responsibilities, work, or other reasons, you can still remain involved. A short summary of the missed session can be shared with you so that you can continue contributing to later workshops if you wish.

You may take a break at any time during a workshop.

### **Do I have to take part?**

No. Taking part is entirely voluntary.

Because these workshops are PPI / co-design activities rather than research, you will not be asked to sign a formal research consent form. If you decide to join, we will ask you to confirm that:

- you have read and understand this information sheet
- you are happy join the workshops
- you understand that your involvement is voluntary
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If you are a healthcare professional, taking part is voluntary and is not linked to your employment, training, appraisal, or performance. Your individual views will not be shared with your employer or manager.

You are free to stop taking part at any time, without giving a reason. If you choose to withdraw after contributing to a workshop, we may keep and use the information you have already shared unless you tell us you do not want us to.

### **What are the benefits of taking part?**

We cannot promise that there will be a direct personal benefit to you from taking part in these workshops.

However, there may be benefits to being involved. You may find it value to

- share your views and experiences in a supportive group
- help shape a nutrition programme that is more relevant, practical, and person-centred
- contribute to improving future support for people recovering after critical illness
- help ensure that the views of patients, carers, and healthcare professionals are all considered in the design of future services and research

Your involvement will help us design a programme that is grounded in real experiences and priorities. This may improve the quality and relevance of the future research study and may ultimately help improve nutrition support for ICU survivors and their families.

### **Will I receive anything for taking part?**

To thank you for your time and contribution, you will receive a £30 e-shopping voucher for each workshop you attend. These vouchers will be provided after the workshops have been completed.

You may want to check whether receiving vouchers could affect any benefits or other payments you receive.

### **Are there any risks or disadvantages to taking part?**

We do not expect any major risks from taking part in these workshops. However, some people may find it upsetting to talk about recovery after critical illness eating difficulties, or experiences from their time in hospital or after discharge.

You do not have to talk about anything you do not want to share. You can take a break, turn your camera off, leave the workshop temporarily, or stop taking part altogether at any time.

Because the workshops will include patients, carers and healthcare professionals, some people may feel less confident speaking in a mixed group. We will make this a priority in how the workshops are run. We will aim to ensure that everyone is treated with respect, given time to contribute, and able to share their views. We will encourage participants to use clear, non-technical language and to listen respectfully to others.

Before the first workshop, participants may be invited to share a short introduction about themselves and any experience they would feel comfortable sharing with the group.

After each workshop, the researcher will be available if anyone would like to speak about any concerns or discuss sources of support.

**Will the workshops be recorded?**

With your permission, the workshops may be audio-recorded to support accurate notetaking. The recordings will only be used to help the researcher remember what was discussed and to support the co-design process. They will not be used for any other purpose without making this clear to you first.

If recordings are made, they will be stored securely and deleted at the end of the project in line with University procedures.

Written notes or transcripts may also be produced. Any identifying details will be removed.

**Confidentiality:**

We will keep your personal information confidential and store it securely.

If you decide to take part, we will collect your name and contact details so that we can organise the workshops and send you the joining information. This information will be stored in a password-protected file on secure University systems and will only be accessible to the project team. It will be deleted once the workshops and related administration have been completed.

If you are taking part as a patient, family member, or carer, we will not collect detailed clinical information about your health, hospital admission, or ICU stay unless you choose to mention personal experiences during the discussions.

If you are taking part as a healthcare professional, we may record your professional role, but we will not identify your specific employer or workplace in any summaries or write-up unless you have given permission and this is necessary.

The ideas shared in the workshops will be used to help design the nutrition programme and inform the next stage of the wider project.

We will ask everyone in the group to respect the privacy of other participants and not share personal information discussed during the workshops outside the group. However, because these are group discussions, we cannot fully guarantee that other participants will not repeat something they have heard.

All information will be handled in line with UK GDPR and the Data Protection Act 2018.

**What will happen to the information from the workshops?**

The information shared during the workshops will be used to help develop a person-centred nutrition programme and to inform the design of a future research study.

The workshops themselves are not research. However, what is learned from them will help make sure that future research is based on the views and priorities of patients, carers, and healthcare professionals.

Information from the workshops may be summarised in project documents, reports, presentations, or academic outputs about how the programme was developed. Individuals will not be identified in these materials unless explicit permission has been given.

**What if I have questions?**

If you have any questions about the workshops or would like more information, please contact:

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